

Gwen, 5 months Ohio

Current PAF Programs Include:

- Provide funding to researchers to find better treatments and a cure for PA;
- An e-mail group for PA families;
- A Patient Care Binder to help keep track of important health related information;
- Educational materials on treatments and on-going research for PA;
- Family matching to enable you to talk to a other PA families;
- A bi-annual PAF newsletter;
- Web-site with information linking you to valuable resources (www.pafoundation.com); and
- A toll free number to contact PAF 1-877-720-2192.

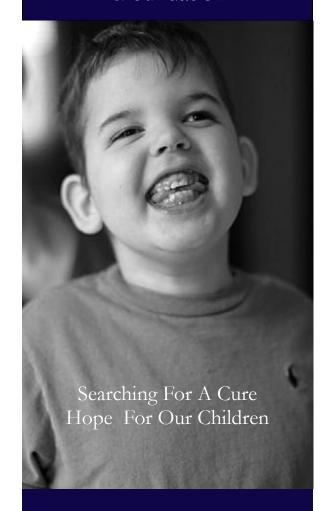


Propionic Acidemia Foundation 1963 McCraren Road Highland Park, IL 60035

Email: paf@pafoundation.com
Website: www.pafoundation.com

Front Cover: Jordan, 6 years Illinois

Propionic Acidemia Foundation



Bringing Research, Support, and Education To Families Affected by Propionic Acidemia

www.pafoundation.com 1-877-720-2192

Propionic Acidemia Foundation (PAF)

The Propionic Acidemia Foundation is dedicated to finding improved treatments and a cure for PA by funding research and providing information and support to families and medical professionals. We are a nonprofit 501 (c)3 corporation. Our vision is to create a future where Propionic Acidemia can be prevented and any affected individual can be cured to live a happy, healthy and productive life.

What is Propionic Acidemia (PA)?

Propionic Acidemia is a disorder that is inherited from both parents. Neither parent shows symptoms, but carry a non-working gene responsible for this disease. It takes two faulty genes to cause PA.

Individuals with PA cannot break down parts of protein and some types of fats due to a nonfunctioning enzyme called PCC. This inability causes a build up of toxins and acids, which can cause damage to the person's organs and be life threatening. During times of illness your child may need to be hospitalized.



Carson, 3 years
California



Lucy, 8 years Kentucky

What is the Current Treatment for PA?

Proteins are necessary for the growth and development of your child. A special formula may be necessary throughout the rest of their lifetime to make sure they receive enough protein for growth and development. This formula will be carefully calculated by your child's doctor and dietitian, specific to their age, weight, growth, and lab values.

When your child begins to eat solid foods, the diet will be low in protein. A low protein diet means lots of fruits, some vegetables, and specially manufactured foods that have little or no protein content. There are great low protein cookbooks and food companies that provide a variety of food choices.

Other medications or supplements like Carnitine and or Biotin may be added to your child's treatment. Additional specialists you may consult include: gastroenterologist, neurologist, cardiologist, ophthalmologist, speech therapist, occupational therapist, and a physical therapist.

The Propionic Acidemia Foundation website and print material are designed for educational purposes only and are not intended to serve as medical advice. The information provided should not be used for diagnosing or treating a health problem or disease. It is not a substitute for professional care. If you suspect you or your children may have Propionic Acidemia you should consult your health care provider.

For More Information

DaytimeEvening Phone Email Affected Individual Age of Diagnosis	Name	
DaytimeEvening Phone Email Affected Individual Age of Diagnosis		_
Evening Phone Email Affected Individual Age of Diagnosis	Address	_
Phone Email Affected Individual Age of Diagnosis	· · · · · · · · · · · · · · · · · · ·	
Affected Individual Age of Diagnosis	Evening Phone	
Affected Individual Age of Diagnosis	Email	
Age of Diagnosis Current Age How did you hear about the PAF? Would you like the PAF to contact you? Yes □ No □ Would you like to be added to our mailing list? Yes□ No□	LIIIaii	
How did you hear about the PAF? Would you like the PAF to contact you? Yes □ No □ Would you like to be added to our mailing list? Yes□ No□	Affected Individual	_
Would you like the PAF to contact you? Yes □ No □ Would you like to be added to our mailing list? Yes□ No□	Age of Diagnosis Current Age	_
Yes □ No □ Would you like to be added to our mailing list? Yes□ No□	How did you hear about the PAF?	
Yes □ No □ Would you like to be added to our mailing list? Yes□ No□		_
Yes □ No □ Would you like to be added to our mailing list? Yes□ No□	Would you like the PAF to contact you?	
Yes□ No□	Yes 🗆 No 🗆	
Comments:	Would you like to be added to our mailing list? Yes□ No□	
	Comments:	
		_
		_

Please Mail this form to:

Propionic Acidemia Foundation 1963 McCraren Road Highland Park, IL 60035